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Center for Urban and Regional Affairs

FINANCING LONG TERM CARE: DILEMMAS AND DECISIONS FACING THE ELDERLY, FAMILY MEMBERS, AND SOCIETY

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Executive Summary

Many questions exist about the role private family resources as well as government programs, such as Medicaid, can and/or should play in financing long term care. The purpose of this study was to look through a family policy lens at the decisions families, and the professionals who advise them, are making about financing long term care. Understanding how families are coping with current policies, programs, and options can provide insight into how long term care can be improved to be more "family-friendly." Forty-five families and sixty-five professionals were interviewed during 1994.

Are Elders Planning Ahead?

- The vast majority of elders had done some type of planning ahead and saving for retirement—but the retirement prepared for was both shorter and healthier than the one they were experiencing.
- Denial of potential long term care risks and a great deal of hope that they will escape such costs is commonplace. Even elders diagnosed with serious chronic illnesses often hope that their own resources will get them through.
- Few had considered long term care insurance and even fewer owned a policy.

What Goals are Families Trying to Accomplish?

- Decisions about finances and care frequently revolve around trying to meet one or more of the following goals:
  - Quality care that meets elders' needs
  - Remaining financially self-sufficient
  - Financial control and privacy
  - Financial security for spouse
  - Leaving an inheritance
  - Protecting the family business
- Conflicts are typical as family members determine which goals are most important and how to allocate limited resources among competing needs.

How are Care Needs Being Met?

- By family caregivers. It is the private informal skills and resources of family members that provide most of the long term care for elders. The average family provided almost six years

(5.85) of intensive family caregiving, keeping the elder in his or her own home or apartment and independent for as long as possible.

- The costs that resulted from the 205 total years these 45 family members contributed are invisible and frequently unrecognized.
- With community supportive services. Community-based services play a key role in meeting the needs of elders, making caregiving manageable, and preventing earlier nursing home placement. Assisted living options, home care, adult daycare, and respite care are examples of critical services supporting families.
- Families stress the importance of having a range of service options which are both affordable and provide quality care. Not having such choices means doing without, living at risk, and unmet needs.
- Families are experiencing a spending down of their financial resources as expenses to pay for assisted living, paid home care, prescriptions, and Medicare co-payments and deductibles are often out-of-pocket. Affordability depends upon a family's income and assets, insurance coverage, and the degree to which community-based services are subsidized.
- In nursing homes. A consistent and clear message from families is the desire to avoid nursing home placement. In reality, families may be forced to come to the realization that nursing home placement may be the best way to provide quality care for the elder.
- Elders in nursing homes were typically the oldest-old, female, and widowed. Nursing home stays for the elders of the families in this study ranged from one month to thirteen years, with two years being the median stay.

Who is Paying for Nursing Home Care?

- An overwhelming majority of families began paying for the nursing care for their elderly family members with private resources (thirty-two of thirty-three families).
- The average family has spent $75,000 on nursing home care with future needs and costs being unpredictable (2.15 mean years of care at an average nursing home cost of $36,000 a year). Consider that nursing home expenses follow both the direct and indirect costs of caring for the elder in the community (mean of 5.85 years).
- Of the thirty-two families who entered private pay, a majority (twenty-five) remained private pay while seven spent down to qualify for Medicaid. The Medicaid application process and actually being eligible often meant feelings of guilt and failure at having to go "on the dole." Having

Medicaid available when the elder's resources were gone and knowing that care should not differ depending upon source of payment was a critical safety net for families.

What about Medicaid Estate Planning?

- Claims that a majority of families are divesting and voluntarily becoming poor to qualify for Medicaid did not hold true for the forty-five families in this study. Overall, there was great variation in how aware families were of Medicaid and the financial protection it provides for nursing home care. Most families were hoping nursing home care would not be needed and, therefore, perceived no need to plan to pay for its cost.
- Families learned about Medicaid upon admission of their elder to a nursing home or through caregiver support groups and at that time may have begun to explore burial trusts and to consider gifting allowed under Medicaid eligibility guidelines. Establishing a burial trust and gifting $500-$2,000 to adult children were fairly common actions. Gifts were often given and/or received with the expectation that they would be used to cover the costs of a private room or other expenditures not covered by Medicaid.
- The intentions and motivations influencing asset transfers are complex and unique to each family situation. Financial security for a spouse is of great concern. Each family story illustrates the unique dynamics and complexities of Medicaid estate planning.
- Attorneys, financial planners, nursing home social workers, and Medicaid eligibility workers each serve a specific niche in helping family members understand potential financing options and consequences. These professional groups see families at different points in the decision-making process.
- Regardless of the specific clientele, almost all professionals find that all too often families are facing a crisis without adequate planning.
- Professionals find a range of opinions among family members on the appropriateness of Medicaid estate planning. Some families, especially the middle class, are using various forms of trusts, prepaid burials, life estates, and gifting to help ensure their assets will pass on to their heirs rather than go to pay for nursing home care.

Attitudes about Financing Long Term Care

- Most family members and professionals expect that they will have to spend some time in a nursing home during their lifetimes and appear to be aware of the high cost of nursing home stays. Most also view planning ahead to pay for potential long term care costs as important.

- Opinions regarding whose responsibility it is to finance long term care suggest individual and family responsibility as the first line of protection, with government programs to protect those in need. Purchase of long term care insurance is seen as a priority by a majority of families and professionals.
- There is some consensus about the limits of family and government responsibility, but less consensus on overall roles and specific expectations for financing long term care.

Improving Long Term Care Financing for Families

As policymakers address issues of financing long term care, the following criteria should be used to determine whether legislation, regulations, and enforcement efforts have the potential to be family-friendly:

- Simplify and integrate. Families and professionals are calling for less complexity in terms of access, eligibility, paperwork, and being able to understand who will pay for what.
- Build supportive systems for families. Families need access to a continuum of affordable and quality long term care community-based services. Services that assist and support informal caregivers as well as the elder play a critical role in extending family, and therefore public, resources.
- A safety net. There are limits to the assets elders have accumulated, especially when care needs extend over long periods of time. For some, Medicaid is the only payment option. The lack of an adequate safety net will mean unmet needs, overburdened caregivers, and spouses at risk of financial insecurity.
- Providing clear and consistent messages. Family members and professionals see a need for more "givens" and consistent messages about what is legal so that they can make informed decisions about paying for long term care. Myths about who pays continue and need to be replaced with a realistic understanding of options and consequences.

The Challenge of Paying for Long Term Care

Medicaid has become a word charged with meaning. To some frail elderly, Medicaid means they won't be turned out onto the streets when their money runs out and they can no longer afford to pay for nursing home care. To other elderly and their family members, it means welfare—the government dole—pure and simple. To state and national policymakers, it represents a large and growing piece of the budget and a vexing political problem with no easy solution. Do you cut Medicaid and make life even harder for the poor, or watch it continue to grow and eat up scarce societal resources that could be used instead for education, crime prevention, or myriad other worthy and important purposes. When the nation's growing elderly population is factored into the equation, the decisions facing policymakers become even more challenging. Similar to other states, Minnesota's single largest category of Medicaid spending is for nursing homes, and total spending is increasing at an alarming rate.

In reality, Medicaid is one critical piece of a complex patchwork of public and private programs that the elderly and their families, as well as state and federal governments, must try to understand when decisions are made about paying for long term care. There is no doubt that the existing long term care financing "system" is proving costly in many ways to the chronically ill, their families, and the bureaucracies involved. Many questions exist about the role private family resources, as well as government programs (such as Medicaid), can and/or should play in financing long term care.

Medicaid-related headlines and ads for professional advice on "avoiding nursing home costs" have led policymakers to ask if elders are qualifying for and using Medicaid who don't really "need" it? Are families engaging in Medicaid estate planning, a practice of intentionally and legally transferring wealth to other family members so that the elder qualifies for Medicaid coverage and avoids using personal assets to pay when long term care is needed? What family resources are really being used to meet the care needs of elders?

A review of the literature found that few comprehensive studies have been published to determine the scope and prevalence of Medicaid estate planning. To date, most research has focused on understanding the impact of Medicaid estate planning on state budgets (Moses 1990; Minnesota Department of Human Services, 1996) or nursing home use (General Accounting Office 1988), rather than how families arrive at decisions or the impact of financing options on families. Some studies share anecdotal evidence from professionals involved in financing long term care indicating that increasing numbers of individuals are practicing Medicaid estate planning (Burwell 1991, 1993; Moses 1990, 1993).

Additional research has used quantitative approaches to examine the affordability of long term care insurance as a financing alternative (Crown, Capitman,and Leutz 1992; Cohen, Greenburg and

Wallack 1987; Zedlewski and McBride 1992). Several studies have examined the financial risks being faced by elders as their long term care needs and expenditures change over time, most use national data sets (Lui, Doty and Manton 1990; Lui and Manton 1989; Mor, Intrator and Laliberte 1993; Short et al. 1992; Spillman and Kemper 1995; Stum, Bauer and Delaney 1996). Adams, Meiners and Burwell (1993) provide a valuable review of the measures used to examine asset spend-down among elderly nursing home users, analyze differences across studies, and call for more state studies to better understand asset transfers. A variety of researchers (such as Arling, Hagan and Buhaug 1992), have also been exploring the feasibility of public-private long term care financing options. Federal and state governments continue to seek new approaches to address long term care expenditures, including home and community-based care and managed care (General Accounting Office 1994, 1996).

Of the research reported, none has attempted to speak directly with elders or their family members about their decision making with regard to financing nursing home care. Reasons for this lack of research include a paucity of available data sources and the secretive and controversial nature of the issue, as well as the sheer complexity of tracking private and public sources of payment for various types of long term care over a period of years.

How one goes about understanding the role private and public resources play in long term care of elders depends in part upon whether one takes a family or a fiscal policy perspective. A majority of existing research has taken a fiscal policy perspective and has attempted to examine the impact of how resources are being used on state or federal government expenditures. In this study the focus is largely through a family policy lens. This means understanding from family members coping with long term care decisions and from the professionals advising them what impact current long term care policies and options have on the family, including decisions about providing and paying for long term care. Using such a lens provides insight into how long term care systems, including government programs and policies, can be improved to be more "family-friendly."

Specific questions addressed in this study include: 1) How prevalent are conscious decisions about financing long term care among families of elders who are at risk? Are elders planning ahead and what are the families trying to accomplish? 2) What types of family and government resources are being used to plan for or protect against the risks of long term care? 3) What decision making processes, roles, and rules are used in regard to financing long term care? 4) What attitudes are held regarding responsibility for long term care? Answers to these questions can help inform policy as decisions are made about how to allocate scarce public resources to protect an increasingly elderly population against financially catastrophic long term care costs.

Study Methods

This study was designed to gather in-depth perspectives from a variety of individuals with insight into family decisions about paying for long term care. Qualitative methods were considered the most appropriate for beginning to understand the dynamics of decision making given the multi-faceted and complex nature of financing long term care and the current lack of research. The methods chosen enable an in-depth understanding of the issue from purposefully selected samples. As a result, insight can be gained about the potential factors influencing long term care in the selected sample. This study is the first known to speak directly with families and to begin to understand decision making about financing long term care.

An advisory group was recruited to assist in refining the research questions, in piloting data collection tools, and in recruiting the sample. Members included representatives from government agencies related to long term care, professional organizations related to nursing homes, as well as individuals with legal, consumer advocacy, and aging services expertise.

The Sample

Families involved in long term care decisions and a range of professionals who assist or advise families about their financing options were recruited to participate in the 1994 survey.

Families. Two types of families were recruited, those with an elder already in a nursing home (n = 33) and those with an elder diagnosed with a chronic illness but still living in the community (n = 12). Compared to the majority of the elderly population, these families were more likely to be dealing with decisions about paying for long term care. Families were recruited through the assistance of family councils in nursing homes and support groups in churches, hospitals, and agencies serving caregivers and individuals with Alzheimer's and Parkinson's diseases. Of the forty-five total families recruited, roughly half were located in a metropolitan setting and half in a rural, agriculturally-based setting.

Families volunteered to participate in the study. They included a broad spectrum, from elders who lived on Social Security as their only source of income to millionaires. A majority were middle class, with accumulated assets up to $100,000 not including the value of their home. Adult children also ranged across the entire spectrum of economic well-being. About three-fourths of the interviews were with the one family member most involved in financial and care decisions—typically a spouse or an adult child. The remaining interviews were completed with two family members who were both involved in

financial decisions. The elder in need of long term care and still living in the community typically participated in the interview, while those in nursing homes were unable to do so.

Professionals. Professionals involved in various aspects of estate planning and asset management related to long term care included attorneys and legal service lawyers, financial planners and accountants, Medicaid eligibility and county human service workers, and social workers in nursing homes. The specific types and number of available professionals varied depending upon the rural or urban setting. Overall, up to ten individuals in each professional group were recruited for a total of sixty-five professional participants.

Data Collection and Analysis

Personal interviews were conducted by trained interviewers using a semi-structured interview format. Questions for families focused on understanding the elder's health history, diagnosis and prognosis, and caregiving (including who was involved in providing care and assistance to the elder). Additional questions focused on decision making regarding care, paying for care, financial options considered and being used, amount and type of planning ahead, and perceptions about the current as well as future long term care system. Questions for professionals focused on understanding their typical clientele, typical questions asked about long term care, planning options and processes used with clients, typical actions taken by clients, and perceptions regarding feasible financial and planning options. Interviews were transcribed and then coded to identify goals, decision-making processes, resource allocation decisions, paying for care, financial options considered and being used, amount and type of planning ahead, and perceptions about the current as well as future long term care system.

In addition to taking part in the interview, all participants were asked to complete a seventeen-item opinion survey which explored their perceptions of long term care risk, degree of control over long term care decisions, and beliefs about family, private sector, and government responsibility for long term care. Professionals also completed two hypothetical case examples to add further insight into financing options and decision making strategies considered by families.

Findings: Perspectives From Involved Family Members

Are Elders Planning Ahead?

The vast majority of elders had done some type of planning ahead for retirement—but retirement both shorter and healthier than the one they were experiencing. Few elders had planned to live so long or were prepared for the potential costs of long term care. Denial of potential long term care risks and costs and a great deal of hope that they would escape such costs seemed commonplace. Elders talked about the unpredictability of health care needs and costs as well as the inability to save enough anyway to meet possible care needs. Even elders who had been diagnosed with a long term chronic illness talked about "hoping" that a limited amount of care would be needed beyond what family caregivers and their own resources could supply to get them through. Fear and worry about outliving their income and assets were very real for some, especially elders who were eighty-five or over. Fear about what the future might bring financially had some elders not refilling medications and doing without needed home care help.

> You saved and were careful and thought you were going to travel and do things and all of a sudden it all goes for nursing home care—you hope that it doesn't happen. *(Wife of husband with Alzheimer's in nursing home for four years)*

> With either of the mothers, if you ever bring up planning ahead or financial issues, heavens, they are not old enough to discuss that. They both hope that they are run over by a car and will never have to face it (long term care). *(Daughter speaking of mother and mother-in-law, both in mid-seventies)*

> We've never seen or talked to anybody about financing . . . we would have to get to a point where it's a concern. Sometimes I think it is better to take your chances, hoping that you die before you get there. What we thought we'd do is go the way we are until we run out (of money) and then figure out what to do. *(Husband with Parkinson's and caregiver wife)*

Planning ahead for many meant living frugally prior to retiring, saving as much as possible from one or two working spouses, and typically investing life savings in certificates of deposit (CD's). Many vowed to use their savings' principal only as a last resort as it was their personal safety net. Daily living needs were often met with a combination of income from Social Security, personal investments, and a pension, if they were lucky. A majority owned a home with a paid off mortgage. It was not uncommon for two minimum wage earners to have accumulated $100,000 in savings over a lifetime, not including the value of their home. While many had worked hard to save, their accumulated assets seemed slight in relation to the $4,000 a month month nursing home care costs some were experiencing. A few elders were living primarily on Social Security income, getting along financially by living in subsidized housing, and limiting spending as much as possible.

> She is using up her money fast, which she had hoped to give to some of the rest of the family, but there won't be anything left if she keeps on living much longer. She didn't make any plans. None of us do, you know. I don't think people should feel, well I've got to put away money now because I'm going to the nursing home. She saved her money and she was very careful with it. I haven't done anything beyond my medical insurance and savings. *(Sister of an eighty-nine-year-old in nursing home)*

A few families who had been approached by long term care salespersons had discussed the risks and cost of nursing home care. For many of the elders over eighty-five, long term care insurance policies were barely on the market at the point when they would have qualified or been able to afford the premiums. It simply was not a feasible planning option. Younger elders talked about not being able to qualify due to health problems, the high cost relative to their income, feeling insurance was not a "sure" thing, and having different opinions than their spouse about the need for such insurance. Only one spouse in the forty-seven families had purchased a long term care policy to provide some financial security for herself, and the remaining assets. While a majority of adult children spoke about the important role insurance could or should be playing in financial protection against long term care costs, only one couple had purchased long term care insurance as a result of their experience with his parents. Several spoke about wishing they would have more seriously considered long term care insurance, and consistently advised younger people to protect themselves with insurance.

> We checked out long term care insurance and were almost convinced to take a policy on me, but it was $2,500 annually for that policy and I think people in our generation have a hard time with these high figures. It seemed as if I might pay for twenty years before I needed it. My husband was not insurable due to his disease. *(Wife in sixties, husband with Parkinson's)*

> We did talk about nursing home insurance, but when was the right time to get it? We had been approached and we discussed it and were really seriously thinking about it, but it is one of those things. You have health insurance and feel you are taking care of it. It isn't a sure thing, but I guess at this point I would advise anybody who can get it and pay for it to pay for it and hope you won't use it. *(sixty-two-year-old wife of seventy-two-year-old husband with Alzheimer's)*

What Goals are Families Trying to Accomplish?

Decisions about finances and care frequently revolved around trying to meet one or more goals. Family members consistently talked about the following goals as being important: a) quality care that meets elders' needs; b) remaining self-sufficient; c) maintaining control and privacy; d) financial security for the spouse; e) leaving an inheritance for the next generation; and f) ensuring that the family business continues. Conflicts were typical as family members determined which goals were most important and how to allocate limited resources among competing needs. Differences about which goals were most

important and how to best reach those goals were found between spouses, adult children and parents, siblings, and other family members.

Quality care that meets needs. Family members consistently emphasized the priority of keeping their spouse, parent, or sibling independent and living at home for as long as possible. Finding quality care to meet the elder's needs was a top priority. Paying for the care and how that decision might impact someone's inheritance rarely seemed to be the driving force in the decisions that were made. Making decisions about care involved more than a dollars and cents cost/benefit analysis. Emotional, physical, social, and financial costs and benefits all had to be weighed from the perspective of the elder as well as the other family members.

The reality of not being able to predict or control an elder's health status or care needs contributes to the worry and fear family members experience. How fast will the Alzheimer's disease progress? How much will medications be this month? Will the level of care needed at the nursing home change with costs going from $3,000 to $4,500 per month? Taking it one day at a time is often required given the unpredictable nature of chronic illnesses as well as the potential for change in a spouse's or caregiver's health and care needs.

> You can't really think too much about the financial part at first. You live with hope, you keep thinking this will get better. I can't predict and I can't plan too much. *(Seventy-three-year-old wife of husband with Alzheimer's, now in nursing home)*

> We are trying desperately not to go to a nursing home. As far as financing, we will just have to deal with that when the time comes. *(Husband with Parkinson's and caregiver wife)*

Financial self-sufficiency. Care for a frail elderly family member is most often viewed as a private, family responsibility. Family resources, unpaid caregiving skills and time, as well as financial resources (both income and assets) are expected to be used for care. "My fair share" was a phrase commonly used as families talked about their responsibilities and obligations. My fair share typically meant: a) family members providing informal care until the physical and emotional costs were too burdensome and the elder's needs could no longer be met, and b) using the income and assets of the elder to pay one's own way while at home as well as when institutional care was needed.

> We feel that your assets are meant to take care of you during your lifetime. Our first responsibility is to take care of ourselves. *(Daughter of ninety-year-old mom in nursing home)*

> As much as possible the system should require family assets to be used to pay for it (nursing home care), except certain things like their home and farm. I think that people who can afford to pay for health care shouldn't expect other people to pay for it. *(Son of father with Alzheimer's)*

> For someone who never had more than what you'd call a little better than minimum wage job, she had accumulated quite a bit of money. She saved a lot and when interest rates were high she had some CD's which made a lot. Financial security was very important to her. All her money will go for her care, but she will receive the same care whether she is on Medicaid or not—she's spent over $90,000. *(Daughter of mom with Alzheimer's)*

A majority of family members interviewed expressed strong feelings about not relying on the government to pay for care except as a last resort. Family members spoke about trying to stretch their personal resources until an elder's death to avoid going on "relief," "the dole," or "the county." Going on Medicaid was most frequently talked about as degrading, ethically wrong, a burden on taxpayers, and shameful. Individuals who had gone through their resources and spent down to be eligible for Medical Assistance consistently reinforced that they were still contributing (or being responsible) as the elder's income sources (Social Security, pensions) continued to be applied to the total nursing home cost.

> Anyone who's been through the Depression has a different outlook on things than my generation does. They have that old fashioned pride, I mean, to be on relief, would be just such a shameful thing that it just doesn't bear raising the question. *(Daughter of eighty-four-year-old mom in nursing home for two years)*

> You have to do things you don't like. We sold the farm and used that money to pay for his care, but then it don't last long when it is $3,000 a month. We've always taken care of ourselves and our family members, and I never wanted to feel like I should be a burden on the county, or state, or wherever it comes from. He (husband) is on medical assistance now and that bothers me. I haven't told him. I don't think he would like it, we have always been people who wanted to be on our own feet. *(Wife of eighty-four-year-old husband with Parkinson's)*

> We though about Medicaid divestment but it doesn't seem ethical. It's mother's money, let's use as much of it as we can to take care of her. The greatest thing in the world would be if mother could pass away the day that she didn't have any money left, that's the feeling among all four of us (adult kids). *(Son of mother in nursing home)*

Financial control and privacy. Maintaining control over financial resources and their use was frequently mentioned as an important goal. Some elders avoided getting advice from local professionals because they wanted to keep their financial information private. Asset transfers to adult children were avoided because of concern about their lack of control over what's been legally given away but is still "mom and dad's." Some family members spoke of avoiding Medicaid for as long as possible to maintain control over care decisions.

> We talked about putting everything into a trust, but decided that wasn't for us . . . you lose all control and we didn't want to do that. At this point we are able to handle the costs. I'm not opposed to having the government support me after I am broke. *(Husband with Parkinson's and caregiver wife)*

Financial security for spouse. In addition to meeting the care needs of one elder in the family, another goal families are trying to meet when a spouse is present is financial security for the healthier

spouse. Families often find that maintaining quality care for the elder competes head on with protecting the financial security of the healthier spouse. Actions taken to protect the healthier spouse, if any, vary with the level of available assets, a spouse's age and health status, and comfort level with spousal allowances under Medical Assistance. For many families ensuring that the healthy spouse would have a place to live and sufficient income for daily living were priorities as decisions were made about the use of current income and assets. Trying to figure out how long one's assets would last, when to cash in what to cover the bills, and how to protect the spouse—all with many unknowns—was often too much for families to cope with at one time.

> Every time we have to dip into savings to pay for some of dad's care, it is a real concern to mom that eventually she is not going to have anything. We try to reassure her that it will be okay, that we can only take it day by day. I think she feels that she is no longer in control and that she is going to lose her savings. We don't know if dad's care is going to increase or if he might live to be 102. *(Daughter of mom (seventy-five) and dad with dementia in nursing home)*

> I am aware that as long as my mother is living, they cannot take all of the savings, but I assume there will be a point where we will have to apply for Medical Assistance. She has very mixed emotions. There is a part of her that going on the county is awful, but there have been so many people that have had to do that . . . so a part of her realizes that is what's going to happen. *(Daughter of seventy-five-year-old mom and dad with dementia in nursing home)*

> I'm not going to lose all that I have. I protected myself (the spouse) so they don't get it all. With my annuity and Social Security, I won't starve, but I'm not going to be able to do the things I planned on doing. They tell all kinds of things you can do. I didn't need most of them. I'm protecting enough so that I will not be dependent on somebody else. *(Husband (eighty-year-old) of wife with dementia in nursing home)*

Leaving an inheritance. While leaving an inheritance to the next generation of family members was a desire and goal for some elders, it was a goal that few were willing to meet at the expense of providing quality care or financial security for the older generation, losing control or privacy, or not being self-sufficient. *If* assets remained after the elder's needs were met and a surviving spouse was financially secure, leaving an inheritance was welcomed. Members of the older generation in a family often talked about leaving a legacy and their hope that they would still be able to do so, if their health would just cooperate.

> Our preference would be to give the money to the kids, but I don't know if that is going to be possible. The kids don't expect to receive an inheritance but they know they will get what's left, if there is anything left. We'll just go the way we are until we run out." *(Husband with Parkinson's and wife)*

> We were concerned about not being able to leave anything for our children, you know if you go to a nursing home it's gone in just no time. I guess that's what we've been saving

for, to take care of ourselves as we grow older. We are very fortunate that we have choices about paying. *(Husband with Parkinson's and caregiver wife)*

I just kept hoping that our money was going to hang on and that the house would sell. I find it very troublesome that people are turning money over to their children—and they, you and I, the taxpayers, are carrying the load when they go on Medicaid by giving away their money. *(Niece caregiver of two aunts in their nineties)*

Mom is so worried about spending a fortune on nursing home care. It's not as bleak as it looks. I guess that is the purpose of saving for your retirement—to carry you through, not to pass it on to the kids. *(Son with father in nursing home)*

Parents often talked about the importance of being able to give small financial gifts to children and/or grandchildren as one type of legacy. In some families, annual or one time gifts appeared to allow parents to contribute to future generations, and allow them to know that not all of their life savings went to pay for the cost of long term care. Adult children spoke about not wanting to accept gifts from parents (for example, $1,000 checks), especially when they saw them living so frugally on so little. It was not uncommon for adult children to be saving such gifts to "give back" if extra money was needed for a private room or for needed extras not covered in other ways.

Mom passed on $5,000 to each child after talking to her family attorney. I don't agree with that personally because we don't really need the money and she may need it to take care of dad. Her thought was, well, I don't want the nursing home to get it all, it is my money so I'm going to do what I please, thank you! *(Son and daughter-in-law of father with Alzheimer's)*

I have a real problem with people who make themselves poor. I don't think it is morally right. I'm not saying they can't give some gifts, but to give away their assets so the state can take care of them, I think that is wrong. *(Daughter of mom in nursing home)*

Mom has gifted $2,000 once to each of us, but the money is set aside and has been used for things for mother. *(Daughters of mom with Alzheimer's)*

Adult children were more often concerned that decisions be made which would benefit the elders than their own generation. Most adult children found themselves questioning if their parents had enough to live a quality life and often perceived themselves as in a better position financially than their parents.

They keep wanting to give money to the children. And we keep saying we don't want it if they can enhance their life now. *(Daughter-in-law of two chronically ill parents)*

I'm angry at my mother for not spending more freely so that she could have enjoyed her life more. The last time she bought a car was in 1987 and she didn't get air conditioning because it was an extra $700, and now I'm spending $4,500 a month of her money on her care. *(Daughter of mom in nursing home)*

A majority of adult children talked about never expecting an inheritance given the realities of their parents' financial situation and the many unknowns associated with longevity.

> I don't think my brother or I, neither one of us has ever thought that we are going to inherit money. I mean we certainly knew growing up that our parents were not wealthy, and so it is one of those things that neither of us would have taken for granted. *(Daughter of dad in nursing home)*

> If I were trying to hang onto an inheritance, I would not have put her in a private room and be paying for it. *(Daughter of mom in nursing home)*

Another adult child felt cheated out of an inheritance. The family had already contributed to thirteen years of nursing home payments and this person knew that the same care would have been provided regardless of whether the elder was on private or public pay. Other family members disagreed. "Others in my family say that money is hers and should be used for her care and did not believe in government financing if she has the money to do it. If there is anything left, then you will get that. We went around on that for a couple years until I felt it wasn't worth the effort because there was strain in the family. I think my mother has gone way beyond what is reasonable."

Protecting the family business. Assets involved in a business were often discussed and treated differently from household income and assets as a form of inheritance. If the older generation was involved in a family business, such as farming, protecting the business so that it could be continued through the next generation of family members was often a critical goal.

How Are Care Needs Being Met?

Family caregivers. Every family story included the key role that family members' skills and resources played in keeping the elder at home and independent for as long as possible. As other research has suggested and the families in this study reinforced, it is the private informal resources of family members that provide most of the long term care for elders. The number of years in which family members assisted in keeping an elder independent ranged from one to fifteen years (see Table 1). Without the intensive family caregiving years, paid help would have been required, needs would have gone unmet, or different care settings explored. Families with an elder in a nursing home had provided a mean of almost six years of care while families currently in the process of providing informal care had provided a mean of two-and-a-half years of care. The "costs" for family caregivers—both direct and indirect—are numerous and typically go unmeasured as well as unnoticed. The total expenditures that result from the 205 total years these forty-five family members contributed are invisible and frequently unrecognized.

TABLE 1. THE CONTEXT OF LONG TERM CARE

ELDER IN NURSING HOME (33 ELDERS)		ELDER IN COMMUNITY (12 ELDERS)	
Elder Characteristics		Elder Characteristics	
Age		Age	
Mean	87 years	Mean	74.5 years
Range	73-99 years	Range	59-83 years
Gender		Gender	
Female	21	Female	7
Male	12	Male	5
Marital Status		Marital Status	
Married	13	Married	8
Widowed	17	Widowed	4
Never Married	3		
Long Term Care Received From Family Caregiving (prior)		Long Term Care Received From Family Caregiving (current)	
Mean/Family	5.85 years	Mean/Family	2.45 years
Range	1-15 years	Range	1.5-3 years
Total Years	180.5	Total Years	24.5 years
Live With Daughter	3 elders	Live With Daughter	2 elders
Community Support (prior number who used)		Community Support (current number using)	
Assisted Living	8	Housing Options	3
Formal Home Care	4	Home Care	5
Day Care	2	Day Care	4
Respite Care	1	Transportation	2
Nursing Home Stay		Senior Meals	3
Mean	32.5 months	Home Maintenance	3
Range	1-156 months	Support Group	2
Median	24 months	Nursing Home Stay (projected)	
		On Waiting List	2

If there was a spouse, they were the likely primary caregiver regardless of gender or their own age. "Til death do us part" commitments are frequently mentioned as motivating spouses. When there was no spouse, it was often a daughter or daughter-in-law who took on the primary caregiving role. Most families had a system of multiple caregivers. Some family members specialized in certain tasks which helped distribute roles among a spouse, adult children, grandchildren, and nieces or nephews. For some family members, caregiving meant frequent visits to help out with daily living or transportation to the doctor, while for others it involved a thirty-six-hour day of caring for a spouse with Alzheimer's.

Community support. Community-based services play a key role in being able to make caregiving manageable and in meeting the care needs of the elder. In almost all families with an elder in a nursing home, some type of community support had prevented earlier placement in the nursing home.

Family members talked about the importance of having a range of options to choose from in community services that are both affordable and provide quality care. For some, the availability of quality assisted living provided needed support between one's own home and the nursing home. For others, formal home care, adult day care, respite care, meals on wheels, and caregiver support helped meet either the elder or family caregivers' needs. Family members also talked about doing without needed services because they were unavailable, not affordable, or because the elder refused to accept help from outsiders.

> Our decision is to take care of mom at home, but we feel we can only do it as long as we can afford to do daycare and as long as we are emotionally and physically able. I don't think people are trying to get out of paying. I would say, enable families to make decisions that are best for them. Make sure services like day care and in-home care are affordable so people can keep the person home as long as possible. *(Two daughters of mom with Alzheimer's)*

Many families experienced a spending down of their private resources while the elder was in the community. Income as well as selected assets were going to pay for assisted living, paid home care, and the frequent co-pays and deductibles not covered by Medicare or Medicare supplement policies. Costs such as dental and eye care, prescription drugs and insulin are examples typically paid for out-of-pocket. Every family situation varies depending in part upon economic status, insurance coverage and benefits, and the degree to which community-based services are subsidized. It is not uncommon for assets from the sale of the home to be used for assisted living, or being able to live in an apartment or condo with some arranged services and support.

Most families talked about how confusing it is to try and understand the constantly changing eligibility, benefits, and payments of various government programs and private insurance. For many, the fragmented delivery and financing of long term care is simply too much to absorb or understand without third party assistance which costs even more money.

Nursing homes. A consistent and clear message from families was the desire to avoid nursing home placement. Families still in the community spoke often about avoiding nursing home placement and hoping that they would be the "exception" as the Parkinson's or Alzheimer's disease of the elder progressed. In reality, families come to the realization that nursing home placement might be the best way to meet the care needs of the elder. Feelings of guilt and failure for not having tried hard enough or doing enough were commonly expressed by the caregivers, regardless of how overburdened or overloaded their role may have been. Caregivers continued to be intimately involved with the elder, regardless of their placement in the nursing home. Daily visits were commonplace by spouses, as were frequent visits by adult children during the week.

Two of the twelve families with elders in the community were on a waiting list for a nursing home due to increasing care needs. Of the families with an elder in a nursing home, elders were typically in the oldest age group, female, and widowed. Nursing home stays ranged from one month to thirteen years, with a median stay of twenty-four months (see Table 1).

Who Is Paying for Nursing Home Care?

Of the thirty-three families in our sample with an elder in a nursing home, all but one had used family or private resources to pay for care during part or all of the stay (see Table 2). Of the thirty-two who had entered on private pay, a majority (twenty-five) remained private pay, while seven had spent down and had qualified for Medical Assistance. Private pay stays ranged from one month to thirteen years, with a mean of just over two years. In our sample the average family, then, had spent $75,000 on nursing home care (2.15 years of care times an average nursing home cost of $36,000) with future needs and costs being unpredictable. These expenditures followed the mean 5.85 years of informal caregiving and out-of-pocket payments for community support.

> Nursing home care isn't the complete picture with my husband because there are doctor bills, dentist bills and eyeglasses—all of that adds up quickly. *(Wife of private pay husband)*

TABLE 2. NURSING HOME PAYMENT SOURCES

PRIVATE PAY (33 ELDERS)		MEDICAID (8 ELDERS)	
Mean Time	2.15 years	Entered on Medicaid	1 case
Range	1 mo - 13 years	Time on Medicaid	4 years
Mean Cost 2.15 x 36,000/yr	$75,000	Potential Cost to Medicaid* 4 x $36,000/year	$144,000
Total Years	75.2		
		Spent Down to Medicaid	7 cases
Total Cost 75.2 x $36,000/yr.	$2,706,000	Mean Medicaid Time	1.8 years
		Range Medicaid Time	1 month - 5 years
		Total Medicaid Time	12.8 years
		Potential Cost to Medicaid* 12.8 x $36,000/yr.	$462,000

* An elder's income continues to be applied to the nursing home cost of care, therefore actual cost to Medicaid is unknown.

What about Medicaid Estate Planning?

Medicaid estate planning involves intentionally transferring assets owned by the elder to other family members so that the elder becomes eligible for Medicaid payments for his or her care. Awareness of Medicaid and the financial protection it provides for nursing home care varies. Most families hope nursing home care will not be needed, and therefore perceive no need to consider such planning. Even when an elder is diagnosed with an incurable, debilitating disease and there are expectations of increasing care, a majority of families do not appear to be consciously planning how they will meet such needs beyond their own caregiving resources. Some have listened and learned about financing options, but have not made specific plans. Some know there are government options, but are not sure about any of the details. Other have heard about Medicaid and consider it a safety net, should their own resources be depleted. Some know some details about transferring assets to become eligible, believe many other families are taking such action, but consider it dishonest, a loss of dignity, and a process that goes against their values and goals.

Most families learn about Medicaid upon admission of the elder to a nursing home and it is at that time that they begin to explore burial trusts and to specifically consider gifting allowed under the guidelines. Many families with an elder in a nursing home have established a burial trust so that money would be available for a funeral, but do not consider this to be Medicaid estate planning or a transfer to exempt assets under Medicaid. Gifting of $500 or $1,000 per year to adult children might also be occurring but not considered as intentional transfers to become eligible for Medicaid. Families in the community often learn about Medicaid through support groups or through friends and may follow up with visits to a professional to learn about specific options. Some families have adult children who are working with or are themselves professionals in financial planning and have heard about potential financing options.

> My mother was always very proud of paying her own way and I don't think she'd really want to have the state pay. I know legally you can take money out, and that her care wouldn't change, except that they won't pay for a private room. *(Daughter of mom in nursing home with sufficient assets for twelve years of care)*

Some families have learned about Medicaid estate planning and made a variety of decisions. One of the thirty-three families with an elder currently in a nursing home had "programmed mom for Medicaid" by establishing a trust in which mom's assets will be inherited by an adult child (see Table 2). In this family, informal care and assisted living had been provided and paid for with family resources for more than eight years prior to needing nursing home care. The inheriting adult child is paying the extra amount for a private room. Another of the thirty-three families who had an elder in a nursing home had planned to apply for Medicaid after reserving $60,000 for nursing home care. Assets had been rearranged

to provide financial security for the remaining spouse and assets transferred to adult children with the expectation that the assets would be used for the frail spouse should the healthy spouse precede her in death. In this case, the Medicaid application was never filed as the spouse died after two months of private pay and seven years of intensive home care by the spouse.

> I could have taken it all and disposed of it, but I didn't. I just felt that we could pay this for some time, the state don't have to pay it as long as I can. I planned to pay about $70,000 or so. *(Husband of wife with dementia)*

Of the seven families who spent down to become eligible for Medicaid, five did not mention any specific planning or divestment activities beyond a burial trust. For most of these families, going through the lengthy Medicaid application process and becoming eligible brought on feelings of guilt and failure. In our sample, the average family who had spent down to go on Medicaid, then, had spent 1.8 years on Medicaid (see Table 2). It is important to recognize that the income an elder receives (Social Security and pensions) continues to contribute to their cost of care after becoming eligible for Medicaid.

For some families who had already spent down or were in the process, knowing Medicaid was available as a safety net and that care would not differ depending upon whether they were private or public pay was a great relief.

> Dad would ask me what the balance was and I would have to say, 'Well, we're getting kind of low dad, we're going to have to cash in a CD.' But when it got to the point of when there wasn't any more money, he didn't want to know anything. It was a stigma for dad to think that he went on welfare. He just said, 'You take care of it,' like just don't even talk to me anymore about money. *(Daughter of dad in nursing home who spent down private resources)*

> She (mom) still doesn't know she's on Medicaid. It would break her heart. I said don't worry about it, we will take care of the nursing home. To them only the worst people in town would have gone on welfare. *(Daughter of mother in nursing home who spent down private resources)*

> You see, we didn't think it would turn out this way. I feel really bad. . . I don't want my mother on the dole, I think that's terrible, but what else are we going to do? We sold her home and she had very little in savings. I'll pay for her private room. *(Daughter of mom in nursing home who spent down private resources)*

> I sat down and figured out how many more months it would be before I had to apply. I found that to be extremely emotional and very, very difficult. Our family has always felt, we take care of ourselves, and if we don't, then someone else in the family takes care. Maybe it is a certain amount of guilt on my part that I am not doing more. It's just very difficult to accept. I think people should take care of themselves when they can . . . but what would happen now if there wasn't any Medicaid for my mother? *(Daughter of mom in nursing home who spent down private resources)*

> We began with an estate of $110,000 and now we're down to $35,000. When you are out of money, you gotta do what you have to do. I want each of the kids to have about

$200 to help offset the payment for the private room. *(Son with mom in nursing home spending down after five years of private pay)*

There were two spend down cases in which planning ahead impacted eligibility for Medicaid. In one family a younger and healthier spouse took action to help protect herself financially by establishing a trust and gifting assets to children. As a result she protected $20,000 and continued to question if she was doing the right or best thing given the cost involved for professional advice. In the second case, the elder had qualified for Medicaid in part because a trust had been created for management purposes years earlier when she became a widow. In this case, four years of nursing home care had been paid for privately as well as four years of assisted living.

Of the three families currently in the Medicaid application stage, two had gifted $2,500-$8,000 dollars to adult children with the expectation that those assets would be used to support the extra cost of a private room which Medicaid does not cover. In both cases, these families had already spent over $100,000 of the elder's care needs from private resources, not counting informal caregiving.

It was about five years ago she had given each of us $500 and we said that this money would be for mom. We will keep her in a private room. *(Daughter of mom in nursing home)*

Another family had a life estate of $60,000, the value of the home, so that their main asset could transfer to the kids and expected that Medicaid would be likely if care needs continued. An overwhelming majority of families who were private pay had estimated the number of years in which they thought they would cover care before assets were depleted and had no intention of divesting assets to qualify for Medicaid before using private assets. In other cases, transfers may have been made to adult children, but sufficient assets remained to pay for the elder's care for many years if needed.

Findings: Perspectives From Professionals

Attorneys, financial planners, nursing home social workers, and Medicaid eligibility workers are professionals involved in decisions about financing long term care. Each professional group serves a specific niche in helping family members understand potential financing options and consequences.

Insight into Planning

There was general agreement among the professionals interviewed that most people are not planning far ahead for how they will pay for long term care. Many professionals said that people start thinking about how they will pay for long term care in the midst of a crisis. In a commonly cited example, mom or dad is very sick and has to go to the nursing home as soon as possible, and the family is scrambling for options. In other cases, the situation may not have yet reached crisis proportions, but existing health problems make it obvious that long term care will be needed in the not-too-distant future.

At the same time, however, many professionals (especially financial planners) acknowledged that more people are planning for how they will pay for long term care today than were doing so a few years ago. Professionals attributed this trend to two factors—the fact that nursing home costs have increased steeply, and increasing media and community attention to the planning options that are available and sanctioned by law.

Families who are doing Medicaid estate planning are generally neither the very rich nor the very poor, according to the professionals. Many of the attorneys and financial planners subscribed to a surprisingly straightforward approach in advising their clients on issues related to asset transfer and Medicaid estate planning. The dollar figure varies somewhat, but they suggest to their clients who have assets in excess of about $400,000 (excluding their home) that they don't need to transfer assets because the earnings on their investment in any year will be sufficient to cover the cost of their care. The underlying assumption here is that people are most concerned about protecting their assets—the principal—and that they will be comfortable paying for their own care as long as they can do it out of their current income and not jeopardize their children's future inheritance or their own nest egg.

Decision Making Realities

In general, professionals find their clients have one of two philosophies—the "I lived through the Depression and I'll pay my own way no matter what" philosophy, or the "I've been a taxpayer all my life, I'm entitled to use government programs, and I'm determined to leave something for my kids" philosophy.

Nursing home costs are the long term care costs most feared by elders and their family members. In Minnesota, nursing home costs range from $25,000 to $40,000 per year, depending upon location and care needs. To protect against the financial risks of nursing home care, families are using a range of options, including various forms of trusts (revocable, irrevocable, living), prepaid burials, life estates, and "gifting programs" allowed within the guidelines of Medicaid. Overall, the professionals interviewed said life estates are the most commonly used transfer option. Elders see the life estate as a way of ensuring that their home will pass on to their heirs rather than being sold to finance their possible future nursing home care.

Professionals rarely have clients who have purchased long term care insurance. Some lawyers and financial planners actively encourage their clients to purchase it, but readily acknowledge that few do. Others suggest that long term care insurance is not a wise investment for many people—the premiums are too expensive to make it worthwhile for the less wealthy, while the more wealthy (those with roughly $400,000 or more in assets) can afford to pay for long term care out of current income, making insurance unnecessary.

The thinking of professionals involved in counseling and advising the elderly on issues related to financing long term care appears largely to be driven by a rational process that takes into account clients' levels of wealth measured against the actual cost of long term care, and by what is allowed by the law. That said, we did observe some variations in interpretation of the law and of Minnesota's Medicaid rules among the professionals we interviewed. For example, one Medicaid eligibility worker reported, "I view a client who is very helpful to their aged parents with more compassion . . . I may read the rules a little tighter" for those who appear to be more greedy and haven't helped their elders out.

Professionals expressed varying degrees of comfort with current Medicaid law and the fact that it does allow a certain amount of asset transfer. According to one rural Minnesota lawyer, "I try and do what the law allows, even if sometimes it makes me grit my teeth . . . My clients are maybe coming from a different place than I am, and they have different concerns and maybe even different values, maybe different needs. If it's legal and it's what they want to do, I'll do it for them, even though it wouldn't be my choice." A Medicaid eligibility worker in rural Minnesota said simply, "I don't believe in giving away of assets."

A Twin Cities financial planner made the point that current Medicaid law creates mixed incentives because it actually allows and provides for asset transfer to occur. In his words, "Is a financial planner doing wrong if they help individuals with assets play by the laws? Don't blame professionals for doing their job—change the laws instead."

Within our group of attorneys and financial planners, there was some variation in terms of the total amount of assets they though an elder would need to be able to pay nursing home costs out of current income and therefore not need to resort to transferring assets. This was undoubtedly the result of different assumptions about the amount of interest that could potentially be earned in the investment market, and possibly of different assumptions about the cost of nursing home care.

The professionals interviewed were generally attempting to approach their clients' situations from a rational perspective. Professionals viewed their clients' decision making processes as anything but rational. According to one financial planner working in a rural area of Minnesota, "I deal a lot with their emotions and their feelings more than just their assets, and a lot of them become very, very dependent..." Professionals readily acknowledged that their clients are often operating in crisis mode, that they're not very well informed, that they are often under severe stress, and that they are outraged by what they perceive to be the unreasonably high cost of long term care.

On the topic of crisis planning, a financial planner noted, "They like to talk about it, but very little action is taken until the crisis is created. I wish I had a nickel for every time someone had come in and said, 'Well my husband just went in the nursing home. Now what do we do?' That happens all too often." On people's general lack of good information, this financial planner said, "Most of the questions get asked by neighbors over coffee, or in the coffee shops . . . That's where a lot of it starts . . . And that's where the myths start too, and the horror stories get shared—over coffee. In fact, I've had calls in the middle of coffee. They're sitting with somebody and one of them will get up and call me. 'Is this true?'" Many of the professionals interviewed reported that it is common for people to come to them with the assumption that Medicare will pay for their long term care. (Medicare pays for long term care only under very limited circumstances.)

In reference to the stress that families are subjected to in making long term care financing decisions, a Twin Cities attorney said this: "The families I deal with are under terrific stress, and they're angry that they're being thrown from one place to another. They can never get straight answers. If they get straight answers in one place, it doesn't prove true in the next place."

On the topic of the high cost of long term care, a lawyer from a rural part of Minnesota said, "People cannot comprehend why it costs so much, that people who earned $3,000 to $4,000 a year their entire life, from 1930 through 1950, and then maybe $10,000 to $12,000 a year in the '60s and '70s are now paying $3,000 to $4,000 per month to sit in a bed . . . People know how much it costs, and it's totally out of relationship to what they perceive care should be. And that's why they want to beat it."

Findings: Attitudes About Financing Long Term Care

Family members and professionals participating in the study were asked to express their opinions about a number of often controversial issues relating to responsibility for long term care. Each participant was asked to indicate their response to sixteen written statements designed to assess attitudes and opinions regarding the risk of needing long term care, degree of control over long term care, and where responsibility for paying for and providing long term care ought to lie (individuals, families, government). Possible responses included were: agree strongly, agree somewhat, disagree somewhat, and disagree strongly (see Table 3).

Risk perception. An overwhelming number of both family members and professionals view a nursing home stay sometime in their lifetime as a likely possibility (86 percent of families; 82 percent of professionals). Both groups were also overwhelmingly aware that nursing home costs are likely to be more than $1,500 per month (90 percent of families and 94 percent of professionals disagreed with statement #2). In addition to risk of needing care and awareness of cost issues, a majority of both families (74 percent) and professionals (94 percent) were clearly aware of the limitations of Medicare in paying for long term care costs. The responses suggest however that 26 percent of family members and 6 percent of professionals may be unclear about the role of Medicare in paying for long term care stays.

Perception of control. Responses to statements #4 and #5 suggest that both groups view planning for potential long term care needs as important. A majority of families (60 percent) and professionals (76 percent) disagreed with "It doesn't help to plan how to pay for your care ahead of time." Just over half of the family members (52 percent) question whether or not their own financial resources will allow them to effectively plan ahead for their care needs.

Who's responsible: individual, family, government roles. Statements 6-16 were asked to help understand opinions regarding the appropriate roles of individuals, their family members, and the government in financing long term care. A majority of both family members and professionals disagreed that individuals should pay their own way no matter what, with strong disagreement being the most frequest response. In contrast, a significant percentage of families (32 percent) and 37 percent of professionals agreed with the statement.

TABLE 3. FAMILY AND PROFESSIONAL ATTITUDES AND OPINIONS ABOUT FINANCING LONG TERM CARE

LONG TERM CARE ISSUES	RESPONSE OPTIONS			
	Agree Strongly %	Agree Somewhat %	Disagree Somewhat %	Disagree Strongly %
Risk Perception				
1. I should think about how to pay for long term care because it is likely that I will spend some time in a nursing home during my lifetime.				
Family members	43	43	10	2
Professionals	18	64	16	2
2. I think it would cost $1,500 or less per month to stay in a nursing home.				
Family members	4	4	12	78
Professionals	4	2	9	85
3. People don't need to plan ahead because Medicare covers long term care costs.				
Family members	0	2	24	74
Professionals	0	2	4	94
Perception of Control				
4. It doesn't help to plan how to pay for your care ahead of time because things will happen as they do anyway.				
Family members	8	31	27	33
Professionals	2	20	36	40
5. I will probably have so little money that I won't have to worry about how to pay for my long term care.				
Family members	21	31	24	22
Professionals	9	33	29	27
Individual Responsibility				
6. People should pay for their own long term care no matter what their circumstances may be.				
Family members	12	20	29	39
Professionals	13	24	29	34
7. A person in need of long term care should plan so that their family members are left with enough money to meet their needs.				
Family members	27	45	18	10
Professionals	27	42	7	18
8. Elderly individuals should make it a priority to purchase some type of long term care insurance.				
Family members	10	49	31	6
Professionals	9	45	25	20
9. It is okay to give away things of value to family members to qualify for Medicaid coverage for long term care.				
Family members	12	39	35	12
Professionals	9	29	31	31

continued...

LONG TERM CARE ISSUES	RESPONSE OPTIONS			
	Agree Strongly	Agree Somewhat	Disagree Somewhat	Disagree Strongly
Individual Responsibility, cont.	%	%	%	%
10. Families should try to assume responsibility for the long term care needs of their members rather than expect help from government programs.				
Family members	24	24	29	22
Professionals	7	40	25	27
11. Families should take care of their elderly members at home, even when they are very ill.				
Family members	2	16	35	47
Professionals	0	20	33	45
Government Responsibility				
12. Government should help poor people pay for long term care so they have money left for other important things.				
Family members	16	43	22	18
Professionals	20	38	20	18
13. Long term care should be provided free for anyone who needs it.				
Family members	16	26	29	26
Professionals	7	20	20	53
14. People who have to live in a nursing home are entitled to have government pay for their care.				
Family members	10	26	43	20
Professionals	5	33	34	28
15. It is fine with me to have part of my taxes go towards paying for long term care for others who need it.				
Family members	21	51	14	14
Professionals	36	45	11	7
16. Government should do more to help the spouse or caregiver who is not in need of long term care from becoming poor.				
Family members	37	43	14	2
Professionals	22	44	24	9

NOTE: Total respondents included family members (N = 51) and professionals (N = 55). Percentages may not equal 100 due to non-responses on specific items and rounding of numbers.

Responses to statement #7 reinforce that planning ahead is considered important by a majority of respondents. Families' and professionals' responses suggest that individual responsibility should include purchasing long term care insurance. Over half of families (59 percent) and professionals (54 percent) agreed with statement #8. Ironically, these are the same family members coping with a lack of planning and families in which neither healthy spouses nor adult children were taking action to purchase long term care insurance. The contrast in stated attitudes and actual actions, while not at all unusual, is important to acknowledge.

Responses to statement #9 reflect the range of opinions in both families and among professionals regarding the acceptability of giving away things of value to family to qualify for Medicaid coverage. Families are very evenly split with 51 percent agreeing in some way and 47 percent disagreeing. Professionals are less evenly split, with 38 percent agreeing in some way and 62 percent disagreeing.

On statements relating to family responsibility, responses suggest that family members' opinions on reliance on family first before government programs is fairly evenly divided among agree and disagree categories. Professionals were most likely to agree somewhat (40 percent) versus 24 percent for family members. A majority of both family (82 percent) and professionals (78 percent) disagreed in some way that families should take care of their family members at home even when they are very ill. These responses suggest there is more agreement about the limits of family responsibility than perhaps about overall roles and expectations for involvement in caregiving.

Opinions regarding some potential roles of government suggest the most consensus among family respondents on recognizing the need for government help for surviving spouses and caregivers (80 percent), willingness for taxes to support long term care (72 percent), and feeling that long term care aid for the poor is important (59 percent). While a majority of both professionals and families agreed that long term care should not be provided free for anyone who needs it, 53 percent of professionals strongly disagreed with statement #13 compared to 26 percent of families. Responses to statement #14 suggest that need for nursing home care in itself is not viewed by a majority as an entitlement to government payment of the care.

Public Policy Implications

The delivery and financing of long term care is a complex policy issue which continues to be addressed through legislation, regulation, and enforcement. Eligibility requirements for Medicaid are being reexamined, especially rules regarding allowable asset transfers. The role of private sector funding mechanisms, such as long term care insurance, and the availability of community-based services are receiving renewed consideration at both the state and federal levels of government. Such policy discussions involve assumptions about the role of the private and public sectors in long term care, the emotional and financial obligations of family members to provide care for elders, and inheritance rights. The experiences of the family members and professionals we interviewed offer important insight for policymakers as the debate about long term care continues.

First, it is important to recognize that both public and private resources are needed. Families as well as various public programs are already spending significant amounts of their own resources. Resources being used by families include caregiving skills as well as income and assets to meet the needs of frail elders. Policymakers should question how far family resources can be stretched before needs go unmet and elders as well as family caregivers are at risk.

Claims that a majority of families are divesting and voluntarily becoming poor to qualify for Medicaid did not hold true for the forty-five families we studied. A few families were transferring assets in anticipation of becoming eligible for Medicaid. Gifts to family members were common and typically ranged from $1,000 to $2,000 per person, smaller amounts than allowed under current gifting laws. Gifts were often given and/or received with the expectation that they would be used to cover the costs of a private room for the elder other expenditures not covered by Medicaid. It is also important to remember that not everyone who divests will eventually apply for or use Medicaid.

It is essential to understand the use of both private and public human and economic resources through the continuum of long term care options, from informal to formal care. To only look at the use of resources in nursing homes or in the community, or to ignore informal caregiving gives an incomplete picture of the total resources that are needed and used. For example, by focusing only on Medicaid expenditures for nursing homes, the private resources that families have contributed go unrecognized.

Future attempts to understand the prevalence of Medicaid estate planning should not simply focus on tracking dollar amounts transferred among family members. It seems essential to understand why transfers are made, the goals families are trying to accomplish, expectations regarding use of assets, and the actual impact of the assets transfer. Getting answers on how prevalent these practices are may not depend as much on the willingness of family members to talk as on how the questions are asked. The

meaning of divestment and transferring of assets varies among family members as well as various professionals. Certain actions taken within legal guidelines may not be perceived as divestment or intentionally transferring assets to becoming eligible for Medicaid. Examples include burial trusts and gifting within the allowed limits.

A systems approach is critical for understanding the true impact of long term care on families as well as on state and federal budgets. Transferring assets to qualify one spouse for Medicaid, for example, may provide the financial protection a younger, healthier spouse needs to stay off Medicaid or other government programs in the future. The complexity of the system comes partly from the number of income streams feeding long term care. Social Security, private pensions, Medicare, long term care policy costs and provisions, and subsidized community services all play their parts. A change in one will make a difference to others.

Improving Long Term Care for Families?

Family members and professionals working with families on issues of financing long term care provided insight into what improving the current long term care "system" for family members would mean. Four key criteria are important for policymakers to use as hard decisions about limited resources continue to be made.

- Simplify and integrate. The current delivery and financing "system" is too complex in terms of access, eligibility, paperwork, and being able to understand who will pay for what. Family members and professionals are spending limited resources on just trying to understand options and consequences before they can make informed decisions. The lack of integration in the delivery and financing of nursing homes, health and social community-based services, and acute care settings such as hospitals and care providers is a major source of frustration for family members trying to provide quality care for an elder. The complexity means that some families "decide not to decide" because the decision making is too overwhelming, and a majority of families must rely on a variety of professionals for information to understand potential options. Professionals struggle to keep up with changing policies and rules, and sometimes offer differing interpretations of what options are legal or what the potential consequences of decisions might be for family members.
- Build supportive systems for families. Family members are trying to meet the needs of elderly family members by providing quality care and keeping them as independent as possible. To do so, they need access to a continuum of long term care services in a variety of settings. Elders and family members clearly prefer community-based care, but equal access,

affordability, and quality issues must be addressed if such services are to be truly "useable." Services which assist and support informal caregivers as well as the elder can play a critical role in extending family, and therefore public, resources. Subsidized adult day care, for example, allows an informal caregiver to provide unpaid care, keep an elder at home, and prevent what may be much more costly institutionalized care.

- A safety net is essential. There are limits to families' availability and ability to pay. A continuum of quality community-based and nursing home care is essential to meet the needs of elders without social support and who have limited personal assets. The safety net needs to take into account the impact of eligibility criteria on both the elder's care choices as well as on financial protection for a remaining spouse. Policymakers should learn firsthand what it's like to complete a Medicaid application, the process of application, and the impact on family members. The lack of an adequate safety net will mean unmet needs, overburdened caregivers, and spouses at risk of financial insecurity. As Medicaid is revisited and states struggle with fiscal responsibility, the risks to elders, their family members, and society as a whole must recognize that for some elders, Medicaid is the only option.
- Provide clear and consistent messages regarding financial responsibility. Family members and professionals consistently emphasize the need for policies that provide more "givens" so that individuals can make informed decisions about how to best protect against the risks of long term care. As one adult child in his 40's said: "If they keep shifting the target around, what most people find is that you never put an arrow into your bow. In other words, don't plan, don't set anything aside, because they are going to shift it on you and there is no point of doing it. You get a lot of gambling because it doesn't matter anymore." State legislatures continue to consider and make changes to make it more difficult to dispose of assets and become dependent on Medicaid. The discrepancy between what is considered legal and what is considered proper confuses both families and professionals. Consistent messages would help reduce the fear and worry about the use of private and public funds.

Education is needed to help current and future generations understand the risks of long term care, the potential financial implications, and the range of family, private sector, and public resources available for protection. Myths about "who pays" continue and need to be replaced with a realistic understanding of financing options and potential consequences. Family members might be more willing to plan ahead for long term care and pay "my fair share," if they know what their fair share will mean financially.

Policymakers face many decisions about the delivery and financing of long term care. It is essential that the perspectives of elders and their family members be heard as these policy deliberations

contine. Their voices will help policy makers perceive the consequences, including the true costs, of the many solutions that must be examined.

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